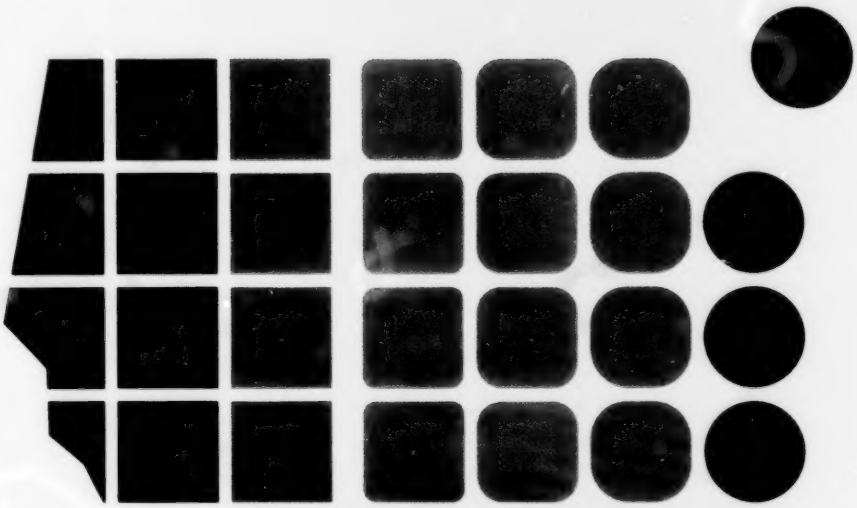
ANNUAL REPORT
1988-89



THE PREMIER'S COUNCIL
ON THE STATUS OF PERSONS WITH DISABILITIES
Alberta

Premier's Council on the Status of Persons with Disabilities

90-02914/

Table of Contents

Message from the Chair	Page 1
Historical Background	Page 3
Council Membership	Page 5
Strategic Management Plan	Page 6
Vision Paper	Page 7
Activity Summary	Page 9
Council Secretariat	Page 13
Structure of the Council	Page 14
Statement of Expenditure	Page 15

Message from the Chair

Statistics Canada estimates that there are over 279,000 disabled people in Alberta (or roughly 12% of the population); of these, 159,000 are aged 15 to 64 years. Historically, these Albertans have been viewed as objects of fear and pity, treated by rejection or charitable paternalism, and seen as neither needing nor wanting the same rights and responsibilities as other citizens of the Province.

These views began to shift about 20 to 25 years ago, as a side effect of the civil rights movement in the United States. Parent and self advocacy groups started springing up, demanding services that would facilitate access to the community, including transportation, recreation, housing, education and physical accessibility. Along the way, groups became more formalized and organized, but divisiveness ensued because there were no unifying philosophy or principles, no "vision" to pursue.

"Daily, people with disabilities struggle with policies and programs that seek to exclude, rather than include."

Policies and programs were developed to meet the needs of those groups that were most vocal and persuasive, but these programs have, over time, resulted in gaps and overlaps and accusations of unfair treatment of some groups. The Province of Alberta has established some of the most generous social programs in the country, including Assured Income for the Severely Handicapped and Aids to Daily Living, annually spending upwards of $150 million on these two programs, yet the programs discriminate against people with certain types of disabilities and help to maintain poverty level existence among disabled people by acting as disincentives to employment and greater independence.

Education and employment levels among people with disabilities fall far below those of non-disabled people. The Canadian Health and Disability Survey of 1983-84 identified 44% of the disabled group as having 8 years of formal education or less, compared to only 17% of the non-disabled group. Just 15% of the disabled group had formal education beyond high school, compared to 32% of the non-disabled group. The ramifications for employment rates among people with disabilities are obvious and are borne out by employment data in the same study: 51.5% of disabled persons in the low education group were employed, compared to 82.4% of non-disabled persons. It is unlikely that "ability" accounts for these differences when motivation and opportunity for education and employment are lacking.

Accessible, affordable housing is inadequate to meet the demand; public/parallel transportation is more likely to be available in cities than towns, but many needs go unmet even in Edmonton and Calgary; technological aids and other personal supports necessitated by the presence of the disability are largely available only to those without means, those who must rely on the public purse for subsistence. Daily, people with disabilities struggle with policies and programs that seek to exclude, rather than include.

There has been a gradual shift in philosophy, in this Province and elsewhere, away from institutional living toward community living, but resources have not shifted to match the changing philosophy. For example, only one third of the Mental Health Services caseload receives institutional services, yet institutions command 76.8% of the budget.

Efforts have been made to influence the Provincial government to rectify some of these issues, e.g., Klufas Report (1983), but these have failed, perhaps because there has never been a body with an ongoing mandate to make things happen. The suggestion for the establishment of a Premier's Council on the Status of Persons With Disabilities found unanimous support among individuals, consumer groups and service providers, who argued that:

- consumers were not being consulted on policies that affect their lives;
- programs and services were fragmented and uncoordinated, and philosophies driving the policies were inconsistent;
- there was a general lack of awareness about the potential of disabled persons to live and work as other citizens do; and
- there was a need for more information about available programs and services.

With the proclamation of the Premier's Council on the Status of Persons With Disabilities Act, the government of this province recognized the need for a mandated, legislated approach to the promotion of "the opportunity for full and equal participation of persons with disabilities in the life of the Province". It created an organization with the potential to achieve this mandate within the next decade.

"...the government of this province recognized the need for a mandated, legislated apporoach to the promotion of 'full and equal participation of persons with disabilities in the life of the province'."

It is a significant aspect of this legislation that the Council reports directly to the Premier. However, I would like to acknowledge the assistance of Mr. Jim Dinning who was appointed by the Premier as his representative to assist the Council in its development. Mr. Dinning's staff, first in Community and Occupational Health and then in Education, have also been most helpful in providing payroll, purchasing and other administrative functions for the Council.

This first Annual Report of the Premier's Council on the Status of Persons With Disabilities highlights the direction the Council has chosen to fulfil its mandate and many of the activities that have been initiated in the fiscal year April 1, 1988 to March 31, 1989. The report will demonstrate the establishment of a coordinated approach not seen before in this Province, and one which I hope will serve as a model for others.

Historical Background

The activity leading to the establishment of the Premier's Council on the Status of Persons with Disabilities took place prior to the time period encompassed in this first Annual Report, however, it may be helpful for readers to have an understanding of the origins of the Premier's Council.

In the mid 1970s, with the advent of a strong lobby by disabled persons for equality and an opportunity to have input into policies affecting their lives, our Provincial Government established an "MLA/Handicapped Joint Committee", consisting of disabled consumers, three Cabinet Ministers, and two non-government MLAs. Shortly thereafter, several pieces of progressive legislation, including Alberta Aids to Daily Living, Assured Income for the Severely Handicapped, and Barrier Free Design Standards, were enacted. This committee was disbanded in the late 1970s. Since that time, organizations representing disabled persons have made numerous attempts to establish a similar advisory body to government.

In March 1987, Alberta lead the country in its support of Rick Hansen's Man in Motion World Tour promoting a greater awareness of the potential of people with disabilities.

The Alberta Organizing Committee challenged groups and organizations representing disabled persons to prepare a brief for presentation to government, outlining the major problems and suggesting one initiative which would improve the status of disabled Albertans. During his historical wheel through Alberta, Rick Hansen took time out to initiate a meeting which he attended, involving representatives from community organizations, Premier Getty and his Cabinet. Following a moving presentation by Diane Earl, a representative of the disabled community, and a challenge from Rick Hansen, Premier Getty committed his government to the establishment of a Premier's Council on the Status of Persons with Disabilities.

"...organizations representing disabled persons have made numerous attempts to establish a similar advisory body to government."

In September 1987, Premier Getty appointed the Honourable Jim Dinning as his representative to assist in the establishment of the Premier's Council. Mr. Dinning appointed a Steering Committee to develop a proposal which would guide government in the formation of such a Council.

Input from agencies, government and the general public was a key component of the Steering Committee process. Respondents to a request for submissions were asked particularly to address the structure and function of the Council, its relationship with consumers, agencies, advocates, associations, and government, and priorities requiring the Council's attention. The Steering Committee also reviewed the structure of a number of other councils existing in Alberta, the President's Committee in the United States, and the existing

Premier's Advisory Council in New Brunswick. By late November 1987, the Steering Committee was able to define the Council's mandate, terms of reference, objectives, activities, structure, and relationship to the community and government in a proposal to the Premier. The proposal was sent with a letter from the Premier to approximately five hundred individuals, agencies and government representatives for validation. In late January 1988, a total of one hundred and four formal responses were received, overwhelmingly in favour of both the need for a council and the recommendations in the proposal. In the two months that followed, government prepared legislation which was introduced as Bill 1, the Premier's Council on the Status of Persons with Disabilities Act. This legislation reflected the recommendations contained in the proposal prepared by the Steering Committee. It was passed and given Royal Assent on May 27, 1988.

On April 15, 1988, Premier Getty announced the appointment of Gary McPherson as the first Chairperson of the Premier's Council on the Status of Persons with Disabilities.

"...legislation...was introduced as Bill 1, the Premier's Council on the Status of Persons with Disabilities Act."

Council Membership

The Premier's Council on the Status of Persons with Disabilities Act specifies that, "The Council shall consist of not more than 15 members appointed by the Lieutenant Governor in Council", of whom one is the Chair. Not more than two of these members may be members of the Legislative Assembly. Beyond these two conditions, the Act makes no specifications about the composition of the Council.

Following the appointment of the Chairperson, there was a public call for nominations for the first Premier's Council in May, 1988. Two hundred and thirty nominations were received from which several potential membership lists were created. These lists were designed to meet several criteria: geographical representation, cross disability representation, and approximately equal number of males and females. The final selection was made by Cabinet and those individuals pictured below were appointed by the Lieutenant Governor in October, 1988. Appointments are made for either two or three years.

The Council's link to Government is a direct one to the Premier through the Council Chairperson. This status and independence have permitted the Chairperson to establish communications with the Ministers and Deputy Ministers that lay the foundation for all future discussions and negotiations, particularly in the policy review area. While this does not assure agreement to every request, it does ensure a mechanism for communicating with those who have the power to make changes.

Back Row, Left to Right: Peter Aubrey, Claudia Moore, Norma Stasiuk, G. (Sandy) Morrice, Randy Hogle, Gillian Oliver, Harvey Ball, Cheryl Crocker, Michael Quinlan, Wendy Bryden

Front Row, Left to Right: Jean Packer, Gary McPherson, Jim Vargo

Strategic Management Plan

When the Premier's Council was established, there was a strong sense in the community that the Council ought to begin immediately advocating for change in specific programs. Although Council members were aware of these expectations for immediate results, there was clearly a need to establish a philosophy and to determine how the Council might effectively use its limited resources to achieve change.

Following group exploration and discussion of the roles Council should play, a consulting firm was engaged to develop a business management plan that would identify those "businesses" on which the Council should focus. The business management plan would also provide a philosophical foundation for the work of the Council. William M. Mercer Ltd. conducted a series of interviews with a representative sample of provincial agencies, consumers and selected government officials to obtain specific input from the community.

The analysis and resulting document identified two businesses for Council: policy review and public education. Given the unique opportunity that exists for this Council, it was recommended that Council accept the challenge of leadership by acting as a catalyst for change in these important areas because these changes will be the legacy to groups and organizations of and for disabled persons after the work of the Council is completed. The identified businesses are consistent with the mandate of the Council as outlined in the Act which lists the following: "advise, report to and make recommendations to the government"; "identify and review current and emerging issues and policies"; and "prepare communication packages containing information respecting disabilities". The management plan strongly emphasized the need for a transformation of both public policies and public attitudes as they relate to people with disabilities if the opportunity for full and equal participation is to become a reality. The plan further outlined goals, objectives and strategies for accomplishing policy review and public education.

The management plan also formulated a mission statement and a set of principles to guide the Council in the performance of their work. Following revision and subsequent adoption of these principles by the Council, a document titled **"Towards a New Vision of Abilities in Alberta"** was released in March, 1989 to the community, including Government, for comment and endorsement. This document gives a historical perspective on attitudes and policy formation with respect to people with disabilities in the Province of Alberta, discusses the transformation of public attitudes and public policy, and outlines a new policy framework. It finishes with the belief system described by the mission and principles.

In 1989-90, the Council will seek full endorsement of this vision paper by the community representing people with disabilities and by the government, and will proceed to develop a public education strategy and an action plan for policy review. Together these will provide a blueprint for change.

Vision Paper

"Towards a New Vision of Abilities in Alberta" is a challenge to persons with disabilities, their representative organizations, service providers and government to forge a partnership and endorse a shared vision that will enable a transformation of public attitudes and public policies to occur in Alberta. This transformational change will result in the realization of "equal status" for all persons with disabilities in this province.

The paper addresses three key areas:

1. Transformation of Public Attitudes and Public Policy

In order to recognize the status of persons with disabilities as one of equality, a shift in focus must occur:

- from the limitation to the person
- from the disability to the ability
- from charity and pity to individual right and responsibility
- from a concept of costs to one of investment
- from institutional living to community living

2. A New Policy Framework

Future policy related to persons with disabilities must encompass three facets:

- Social perspective - a commitment to a dignified and humane society ensuring quality of life for all Albertans
- Economic perspective - a recognition of the significant economic and social contributions to be made by many persons with disabilities, and that support and assistance are an investment in the individual, regardless of the nature or size of the return on that investment.
- Citizenship or Individual Rights perspective - a commitment to equality for all Albertans

3. Principles to Guide Policy Development and Public Education

The Council believes that, if it is to accept the challenge of improving the status of persons with disabilities, it must propose a belief system which government, organizations and individuals can all accept and which will guide public education and policy development in the foreseeable future. These principles are:

INDIVIDUAL RESPONSIBILITY AND PERSONAL CONTROL

- A system is needed that ensures individuals have the right and the opportunity to make informed decisions and choices about issues affecting their lives.
- Mechanisms to support and assist individuals to make decisions must exist and must be provided in a way that will maximize freedom of individual choice, without denying the necessity to intervene where those decisions would clearly result in purposeful self-destruction or harm to others.

•Personal and financial supports must be in place for those who need them so that genuine options exist from which to choose.

• Freedom of choice must encompass the concept of dignity of risk and includes the implications/ consequences of risk taking. A disability does not relieve individuals of responsiblity for their own lives and their obligations as citizens.

OPPORTUNITY FOR FULL PARTICIPATION IN COMMUNITY LIFE

•Individuals with disabilities must have a range of options for living and working in the community that provides opportunities to maximize participation in the life of the community of his or her choice.

•Support systems must be in place to facilitate each individual's efforts to reach their full potential.

EQUAL STATUS,PERSONAL CONTRIBUTION AND INHERENT WORTH

•Persons with disabilities must be recognized for their abilities and equal status and, therefore, any support is viewed as a means to enhance their abilities and to recognize their equal status as citizens.

•The concept of return on the investment must include the economic contribution people will make in terms of taxes and dollars reinvested in the community, community service, societal enrichment, and enhanced quality of life.

•Public education and policy must encompass and create an awareness of the interrelationships of social, economic, and human rights issues.

EQUITY OF OPPORTUNITY

• Barriers to participation in society that are purely a function of disability must be removed in order to create an equal playing field. Among the barriers are lack of public awareness, lack of flexible and available support services, and financial costs directly related to a disability.

•The impact of additional costs related to special conditions incurred directly as a result of disability must be substantially reduced or eliminated.

CONSUMERS AS CONSULTANTS

• Consumers and their families/advocates must have input into policies that have potential to impact on the status of disabled persons.

• Consultation with consumers must occur as a matter of course whenever changes are being considered, thereby acknowledging the value of that input and the right of individuals to influence their government.

Activity Summary

Long Term Care Study

The Mirosh Report, released in February 1988 and titled **"A New Vision for Long Term Care"**, was limited to an examination of the long term care needs of seniors in Alberta. Community reaction strongly suggested that there might be substantial differences in the needs of young disabled adults despite some obvious similarities. With this in mind, a proposal was prepared to conduct a study that would focus on young disabled adults.This study began early in March 1989, co-sponsored by the Premier's Council and Alberta Health. Chaired by Cheryl Crocker, a member of the Premier's Council, the Advisory Committee will examine the long term care needs of young disabled adults (18-64 years of age) and the necessary service requirements to facilitate independence and productivity in these individuals.

A consultative process was planned in which individual and group interviews were conducted by Humanite Services Planning throughout the province, with the Advisory Committee coordinating the activity.

The purpose of this study is to develop a system that can provide an integrated service continuum for young adults with physical disabilities. To this end, analysis will focus on the immediate needs in the long term care system, including community and institutional needs, and on the policy requirements to develop the long term care system for the future. The study will be completed early in the next fiscal year.

Rehabilitation and Long Term Care Consultation

The Council co-sponsored, with the Premier's Commission on Future Health Care, a one day workshop for people with disabilities and private, non-profit and government service providers in the rehabilitation and long term care fields. It was held in Calgary on December 12, 1988.

The intent of the workshop was to provide a forum for participants to discuss their concerns and make recommendations to the Council and the Commission in a number of areas: hospital based rehabilitation, facility based long term care, rehabilitation specifically for seniors and children, professional resources in the community, and ongoing community supports for adults. Rehabilitation and long term care was one of three areas identified for study by the Commission.

In preparation for the consultation, the Council was largely responsible for identifying and recruiting service consumers and some service providers who would be able to represent a broad perspective in discussing issues and making recommendations. In addition, a consultant was retained by the Council to represent the interests of the Council in planning and executing the consultation process.

One hundred and ten people from across the province participated and the final report, **"Finding Alternatives that Foster Health, Personal Control and Responsibility, and Community Participation"**, consolidated consultants' background reports and the issues and recommendations arising from the consultation.

Consultants and Subcommittees

The Council secretariat, under the direction of the Premier's Council, is responsible for gathering such information as may be needed to understand the breadth of an issue or to gain a sense of direction for change. Since the secretariat is purposely kept small,it is often necessary to obtain outside help on an ''as needed'' basis.

In preparation for the establishment of Task Teams to study the identified priority issues, the secretariat secured the services of seven individuals, each with expertise in one of the following areas: transportation, accessibility, education, recreation, personal supports, financial supports, and systems of direct payment. Beginning in March of 1989 each of these individuals prepared a background paper in their area of expertise, taking a cross disability approach to outlining the current policies, gaps or overlaps in service, and suggested solutions to reduce inequities. Papers on housing, training and employment were prepared by the secretariat. The purpose of the papers is to ensure a common level of understanding of the issues by all Task Team members, to serve as a starting point for discussion and development of recommendations.

Representatives of people with mental illness and hearing impairments challenged the use of a cross disability approach to the issues under scrutiny, saying that they did not believe that such an approach would adequately identify or address the needs of these particular disability groups. In consultation with the Council, the secretariat agreed to establish two sub-committees whose role would be to examine all of the identified issue areas from a single disability perspective, and to prepare a report for the Task Teams.

Subcommittee members were chosen in consultation with representatives of the disability groups in question and the subcommittee chairpersons were invited to sit as ex officio members of the Task Teams when they are established, in order to ensure that the recommendations of their subcommittees are given full consideration.

Newsletter

Late in 1988 Council saw the need for a communications vehicle to reach major stakeholders, especially community agencies and key government officials. The purpose of such communications would be to provide up-to-date information on Council activities. The first effort resulting from this thinking was **''Interplay''**, released in December of 1988.

In an effort to increase readability, the newsletter was revamped and given a new format and title in the spring of 1989; **''The Status Report''** is the result of this exercise. Much of the credit must go to Polar Artworks for creating the new masthead and renaming. The new title reflects the emphasis placed by Council on the equal status that must be afforded to persons with disabilities, and it is hoped that the new format will assist Council in sending this message to key stakeholders.

Activity Summary

Alberta Information Network

Easy access to information of interest to persons with disabilities was documented as a major concern in 1987 in a brief to Premier Getty by a coalition of organizations representing disabled persons, in 1983 in the Klufas Report commissioned by the Department of Social Services in Alberta, and in 1981 in the federal document, Obstacles.

At the federal level, in 1986 the Department of the Secretary of State announced the establishment of the Walter Dinsdale Centre for the empowerment of Canadians with disabilities. A major initiative of that centre has been the establishment of **Disability Information Services of Canada (D.I.S.C.)**. DISC is a national computer network which promotes the exchange of information among persons with disabilities and those who share common interests and concerns. DISC promotes the development of information resources, at the local, regional and national levels, which are controlled by persons with disabilities and are designed to meet their needs. These resources can then be shared utilizing the DISC computer network. At present there are, on the average, 10,000 calls to the system per month.

Because DISC was designed to establish a "link" or "highway" for the sharing of information by disabled persons and organizations, a **comprehensive regional information database** must be added to the system if it is to adequately address the information needs of disabled persons.

One of the first projects undertaken by the Premier's Council on the Status of Persons with Disabilities was to fund a study to develop **"An Information Strategy to Ensure Open Access To Information for Albertans with Disabilities"**. This study proposes the development of a regional information database, networked in Alberta through a dedicated computer trunk line between Edmonton, Calgary, and Lethbridge, and integrated with the existing DISC system. The regional system is referred to in the proposal as the Alberta Information Network.

While the Premier's Council on the Status of Persons with Disabilities strongly supports the development of an Alberta Information Network, the Council does not see the operation of such a system falling easily within its mandate, given that the Council will be disbanded in 1998. Therefore, the Council is working with the Walter Dinsdale Centre and other organizations, in a facilitating role, in an attempt to work out the appropriate administrative structure and identify the appropriate funding sources for such a network.

Public Education

The Council's Vision paper, **"Towards a New Vision of Abilities in Alberta"**, emphasizes the need for a transformation of both public policy and public attitudes. As a result public education was identified as one of the businesses in which the Council must involve itself. Most importantly, the Council must "address a spectrum of deep-seated cultural beliefs which contribute to fear, limiting assumptions, and misunderstandings regarding individuals with disabilities" (Towards a New Vision of Abilities in Alberta). Policy change cannot occur in isolation, but must happen in conjunction with a concerted public education strategy.

Thus began the development of a public education strategy in February, 1989 subsequent to its identification as one of the businesses of Council. A meeting was held with Mark Gregory of the Department of Education, Communications Branch on February 16 and it was decided at this meeting that a public relations firm should be engaged to develop a strategy for the Council in this area. On March 13, Ladd Communications was contracted to perform this work for the Council and they are expected to complete their work early in the 1989/90 fiscal year. The development of an effective public education strategy has begun as a first step in the transformation of public attitudes.

Activities and Issues Survey

During the information gathering/public consultation phase of the Steering Committee's work to develop a proposal for a Premier's Council, many individuals and groups also presented their views on the activities and issues they felt should be addressed by the Council. In order to develop some consensus on priorities for the Council this information was used to develop a questionnaire that was sent to individuals, organizations representing people with disabilities, service providers, and government representatives. Questionnaire development and analysis were managed by Humanite Services Planning as an extension of their contract to manage the Steering Committee process.

Approximately 1500 questionnaires were distributed in November/December, 1988 and 577 were returned completed. Analysis of the results identified two high priority activities for the Council: legislation and policy review, and coordinated advocacy. The three top ranked issues were living in the community (a cluster that includes transportation, housing, recreation, accessibility, and personal and financial supports), employment and education.

The Council will use this information to guide the establishment of Task Teams that will explore the issues and make recommendations for policy change.

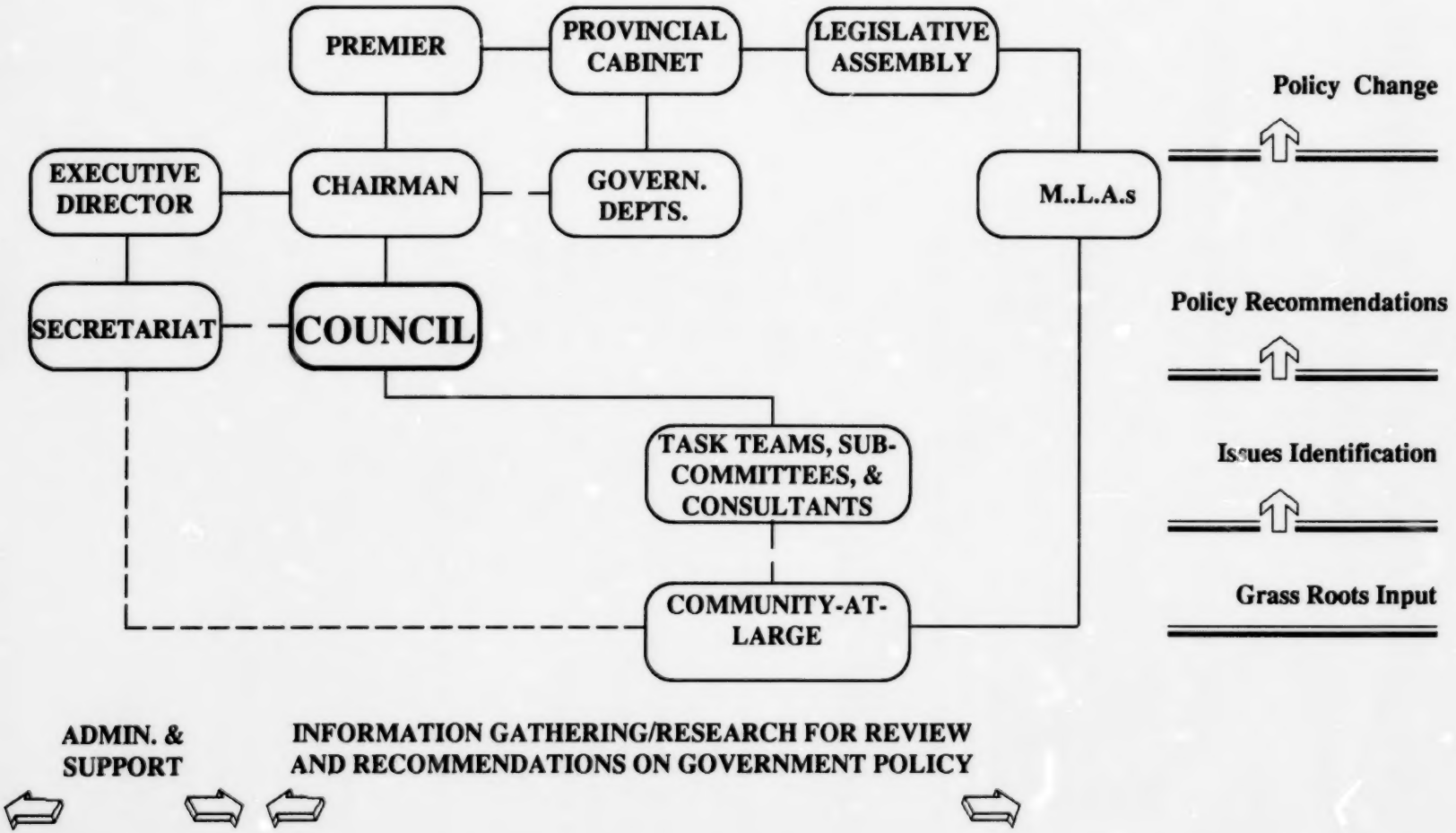
Council Secretariat

Keeping the Council running in its daily operation is a full-time job that is handled by the Council Secretariat. Located at #250, 11044 - 82 Avenue,Edmonton, the main focus of the Secretariat is on communication with government and community agencies. Towards this end the Secretariat makes extensive use of the fully automated Council office. The database is a key component of this automated environment and management of this database allows the Secretariat to effectively communicate with both government and the community.

Use of fully automated office systems has meant that the administrative aspect of Council could be handled with a minimum of staff. Outside consulting has been used to augment the work of the secretariat as required.

The secretariat staff is composed of Eric Boyd (Executive Director), Wendy Buckley (Executive Assistant), and Dale Jacobs (Information Officer). In his capacity as Executive Director, Mr. Boyd is responsible for the supervision of both staff and consultants involved in information delivery, policy evaluation and development, and liaison with government and the community. As Executive Assistant, Ms. Buckley is responsible for all Executive Secretarial functions as well as assisting the Executive Director with administrative processes, especially those which pertain to the budget. In his duties as Information Officer, Mr. Jacobs is responsible for preparation of materials relating to Council activities, development and maintenance of an information database, and background research in support of the Council's and Executive Director's initiatives. Dr. Fran Vargo and Mr. Rod McPherson have been engaged as consultants on an ongoing basis in the roles of Special Projects Coordinator and Computer Systems Support Person respectively.

STRUCTURE OF THE COUNCIL



STATEMENT OF EXPENDITURE

Year Ended March 31st, 1989
Unaudited

	AUTHORIZED	EXPENDED
MANPOWER GROUP		
Salaries & Wages	$170,000.00	$ 44,717.70
Payments to Contract Employees	——	25,341.00
Employer Contributions	22,500.00	4,349.09
Allowances & Benefits	2,000.00	605.00
TOTAL MANPOWER GROUP	$194,500.00	$ 75,012.79
SUPPLIES & SERVICES GROUP		
Travel Expenses	$ 39,814.00	$ 24,168.86
Advertising	——	10,800.93
Freight & Postage	15,000.00	4,869.43
Rentals	37,000.00	5,159.15
Telephone & Communications	25,000.00	3,461.82
Repairs & Maintenance	5,000.00	144.99
Contract Services	201,433.00	229,076.11
Data Processing Services	2,500.00	——
Hosting	10,000.00	2,454.98
Materials & Supplies	32,000.00	26,558.21
TOTAL SUPPLIES & SERVICES GROUP	$367,747.00	$306,694.48
FIXED ASSETS GROUP		
Data Processing Equipment	$ 73,000.00	$ 64,455.23
Audio-Visual Equipment	5,000.00	2,750.96
Reproduction Equipment	10,000.00	——
Office Equipment	28,000.00	5,325.50
TOTAL FIXED ASSETS GROUP	$116,000.00	$ 72,531.69
TOTAL EXPENDITURE 1988/89	$678,247.00	$454,238.96